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ABSTRACT

Written for Canadian parents of young children with special needs, this handbook provides information on ways in which parents can work with professionals (physicians, teachers, other school staff, social workers, psychiatrists, psychologists) in selecting and monitoring services for their special needs child. The first section considers the foundations of parent-professional relationships, and presents an historical overview of such relationships. Information is presented on parents' and professionals' attitudes and needs, and on obstacles, solutions, and myths and realities regarding an effective parent-professional relationship. The second section lists the following checklists of good practice: (1) features that contribute to positive parent-professional interaction in a birth hospital; (2) options for parent involvement in early childhood services; (3) professional attitudes and practices that encourage confidence in the parenting role; (4) parent questionnaire for monitoring home-based programs; (5) features that encourage partnership in transition from one program to another; (6) preparing for a conference; (7) what to look for when choosing a group setting for your child; and (8) areas of particular importance for special needs children. Resources (mostly books, manuals, and journal articles) listed in the final section deal with the historical perspective, general parenting and child development, parent development, parents' stories, first person accounts, a family perspective, professional development, rationale for parent-professional partnerships, program models for partnerships, and bibliographies. A form for making a resource recommendation is also provided. (CB)

ED 276 174

WORKING TOGETHER

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INTRODUCTION

This handbook is written for Canadian parents of young children with special needs who are seeking support or information from professionals. It attempts to provide information in a variety of ways that may help parents to work more effectively with professionals, and to select and monitor services for their child.

In the past, parents and professionals worked quite separately. Information exchange was limited and parent involvement in programme planning or decisions regarding their child was rare. Today, parents are increasingly involved in services and professionals are recognizing the value of this. We believe that increased collaboration between parents and professionals benefits the child.

In preparing this handbook, we asked parents across Canada what helps them in forming good working relationships with professionals. We also surveyed professionals and professional literature which is not readily available to most parents. One of our best sources in this was professionals who were also parents of children with special developmental needs. Both perspectives, parent and professional, are presented in this handbook. The issues are complex, and in some areas, overlapping. We hope that the experiences and insights shared here will enable us to form closer working relationships.

For your convenience, each quotation is footnoted (indicated by a raised number) and the source can be found at the back of the text. Many of our quotations are taken from books which you might find of interest and are described in the resource section of this handbook.

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WORKING TOGETHER

A Handbook for parents and professionals

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WHAT WE MEAN WHEN WE SAY . . .

Throughout this handbook we will be using specific terms to describe the children, their parents, and those professionals who deal with them. We will also examine the culture in which they live and the concepts which affect their working relationships. Please consider these definitions as you read this publication.

Family - "A unit of at least one child and one adult whose moral and emotional claims on one another create a tapestry that each family member acknowledges as 'my family'." [1] This definition takes in the traditional extended family, the new nuclear family, the single parent and communal families, and it does not judge different lifestyles.

Children with Special Needs - Children up to six years of age who are unfolding at a significantly slower pace than normally anticipated in one or more major skill areas. Within this group are children with diagnosed handicapping conditions, and children who are slow but for whom no diagnosis has been made.

As much as possible, we do not use restrictive terms such as mental handicap, physical handicap or sensory handicap. They are irrelevant for parents if their son or daughter does not have a firm diagnosis of one of these conditions, or has more than one handicap.

Parents - Natural, adoptive, foster, protectors, guardians. The significant adults in the lives of children with special developmental needs.

We believe that parents as individuals are as different from one another as their children are. Family backgrounds, ages, religious beliefs, education, economic levels and self-concepts all vary. Parents also differ in the ways they look at their child's delay or handicap.

Professionals - The people who provide the services to families of children with special needs: teachers; nurses; nutritionists; infant development consultants; occupational and physical therapists; physicians; social workers, to name a few.

It is important to remember that professionals are individuals who are as different from each other as parents. These differences include their general attitudes toward others, and, more specifically, their beliefs and values relating to parents and children with special needs.

Parent-Professional Partnership - A cooperative relationship between parents of the child with special needs and the professional(s) who provides services to the child and/or the family. It is based on mutual respect and joint decision-making. Partners share, partake and associate; they are colleagues. Both must work at keeping communication lines open and both must see their contributions as equally valuable. Forming a genuine partnership between parents and professionals is a new approach to an old relationship. It is not easy, but we believe it benefits the child.

CHANGES OVER TIME

Traditionally, physicians, psychologists, psychiatrists and social workers have been in contact with parents of young children with special needs. The physician informed parents about their child's medically diagnosed special needs. The psychologist provided a more detailed psychological and educational diagnosis. Psychiatrists or social workers assisted parents to adjust to the realities of the child's present and potential circumstances.

Recently, the roles of these professionals have expanded. Physicians are increasingly called upon to supply information about the child's development and to help parents find support services in the community. Psychologists are asked to give parents specific training in behaviour management skills suitable for their child. Psychiatrists and social workers are requested to help parents cope independently and find resources to help themselves. Professionals are asked to develop greater awareness of and respect for the demanding everyday realities of parenting a child with special needs. And, at last, parents are getting some credit for the demanding job they have done in the past with their children.

Many other professionals are making contact with parents of special needs children. Nurses, teachers, clergy, occupational therapists, physiotherapists, speech therapists and infant development specialists are all facing the challenge of learning how to help parents help their children.

With all these professionals converging upon them, parents must meet challenges and opportunities for involvement they did not have before. In the past, parents and professionals had set roles: the active professional and the passive parent. Today, professional approaches to working with parents vary greatly, reflecting historical changes in parent-professional relationships.

Peter Mittler[2] has identified three distinct phases through which parents and professionals have passed in their encounters over time.

Initially, many professionals provided little help or support to parents. Advice often had minimal practical value and tended to take a negative and fatalistic outlook. The child was seen simply as the target of intervention; the relationship between him/her and other family members was not thought to be important. Professionals were consulted solely for their presumed expertise within their own areas, as people with special training that parents did not have and could not achieve. Parents were expected to be passive recipients of professional services, capable of reacting but not initiating. Professionals sought to remain dispassionate and aloof.

The second phase called for limited parental involvement. Focus and direction was given to the parent by a specific set of activities prescribed by the professional. This approach required the parents, particularly the mother, to become the target of intervention instead of the child, as professionals tried to transfer some of their specialized skills and techniques to her. Assuming that more parental involvement was better, parents were expected to give direct help to their child, often without consideration for other demands on their time and energy. The assumption underlying this approach was still: Professionals know best.

The third phase, our contemporary outlook, emphasizes the importance of both parties developing and sharing a cooperative working relationship. This approach accepts that there is no **best** way for parents to help their child. Instead, each family should be assisted to solve its own problems, working in partnership with the professional.

"...Parents should gain competence in solving the problems they encounter with their infants not by getting the 'right' solution from the 'expert', but by getting the kind of support, information and encouragement that enables them to discover which solution is best for them *and* their *needs at that particular time."* [3]

FORCES FOR CHANGE

Many trends have emerged in our society during this century, particularly in the last thirty years, which affect parents and professionals involved with children with special needs. A few of these trends grew out of areas relating to specific handicapping conditions, others from more general areas.

The Parent Movement in the Field of Mental Retardation*

The general public in North America, in the first half of this century had an unfounded belief that persons with mental handicaps were a menace to society and civilization. They believed that poverty and crime were linked to mental retardation and these social ills would be cured if mental retardation could be controlled or eradicated. Mental retardation was believed to be inherited. Therefore, families were considered 'tainted' if a family member was mentally handicapped. To 'protect' society, thousands of persons with mental handicaps were separated from their families and segregated into large institutions. Sterilization laws were passed and upheld by the courts and thousands of children and young men and women were sterilized.

During this period, the best professional advice available to parents of a child with a mental handicap, was that the child and family would be much better off if the child was placed in a residential institution. This advice was offered in good faith. Most professionals believed, as did the general public, that institutionalization protected the child, who was happier with his 'own kind'; it protected the family, who would not be able to cope; and it protected society from persons who would practice and teach immorality.[4]

Parents faced a life of frustration and isolation, a double isolation. First, the child was kept apart from other children and the family stayed away from other families. Second, the community offered few, if any, opportunities or encouragement for integration.

World War II brought many changes to our society in North America. It brought prosperous economic changes, scientific advances and expanded government control over areas that had been previously in private hands. It caused us to re-examine our attitudes and values about minority groups and to accept increased social responsibility for those in need. In addition, myths relating to handicapped persons, such as criminal tendencies or inability to learn, were dispelled by changes in attitudes, values and improved scientific research.

The parent movement in the field of mental retardation grew out of this increased consciousness and was the single most important development to influence services for persons with mental handicaps and parent/professional relationships. It started slowly.

From Segregation...

In the 1940s and 1950s, parents started to break out from isolation and reach out to other parents. They met through advertisements placed in local newspapers or by word of mouth. Each had a son or daughter, rejected by the larger society. Each believed that his or her son or daughter had the right to a fuller life in the community and was prepared to work to establish that right.

What happened must be called a Movement because almost overnight across North America and in many other parts of the world, parents met and formed groups. These local groups worked separately from each other at first, under a variety of names, but as groups expanded, they made contact and combined their efforts by forming provincial/state and national organizations. The first local association for the mentally retarded in Canada started in Ontario in 1947. The Canadian Association for the Mentally Retarded was formed in 1958 and today in 1984, there are over 360 local branches across Canada.

**The best description we have found of the evolution of the Parent Movement and the tremendous influence it has had in Canada is found in the Orientation Manual on Mental Retardation [1981 Revised Edition], published by the National Institute on Mental Retardation. We have included parts of this description in this manual, but highly recommend that you read the full account of the Orientation Manual. For an annotated description of this excellent resource, please consult our resource section*

In the early days, parent groups faced many professionals who were uninterested and uninformed, who wished to protect their domains against parent involvement. Parents were considered irrational and unrealistic in their demands and not able to understand 'professional' perspectives or information. Some professionals believed that parents had no right to question or to challenge their decisions. Although much of the conflict arising from the confrontation between parent groups and professional organizations was not made public, it represented a direct challenge to the established order in mental retardation, an order of, for, and by professionals.

...To Integration

The parent movement brought changes in public and professional attitudes about handicaps. As Dr. Henry Dunn has stated:

> *"Since the Second World War, parent groups have been formed and organized increasingly and it should be frankly admitted that the great improvement in the facilities for the mentally retarded in all Western countries appears to be due largely to the increased activities of the parents, rather than that of the medical or teaching professions."* [5]

Perhaps the most valuable gain from the struggle was the discovery of better ways of providing services to persons with handicaps. From wanting more for their sons and daughters, parents moved to **demanding** more. In particular, parents became dissatisfied with a model of care which segregated their children from the mainstream of society. Instead, they began to advocate that persons with handicaps should have access to the services of the regular community - a thrust that is still taking place.

The record of one Canadian local Association for the Mentally Retarded demonstrates how dramatically the parent movement affected local services, (or non-service), over a 20 year period:

1955 Parent Council forms;
1955 School program starts in parent's home;
1956 School moves to larger quarters (donated);
1958 School building open (built with the help of service clubs);
1959 Teen club and recreation programs started;
1965 Preschool programme begins;
1965 Association hires staff person for its own office;
1967 School district takes over Association school;
1968 Child development demonstration project started;
1969 Large residence opened for adults;
1970 Adult activity program started;
1971 Sheltered workshop opens in new building (built with service club help);
1972 New child development centre opened;
1972 Demonstration of public school integration begins with AMR backing;
1973 Two group homes opened (children);
1974 Starts larger demonstration of public school integration;
1975 Two more group homes open (adults);
1975 Infant Development Programme starts;
1982 People First formed

The parent movement in mental retardation is one of the most successful world-wide consumer citizens' movements in history. It protested the established order; it provided creative solutions to problems; it implemented services when needed and it did these all by utilizing existing democratic processes.

Other Forces

Other trends emerged in North America after World War II. The civil rights and consumer movements, and increased research into child development have influenced all people in our society in varying degrees. These trends have had considerable impact on the parent movement and the relationships between parents and professionals.

The Civil Rights Movement

The systematic destruction of certain minority groups in Europe prior to and during World War II awakened North Americans to their own prejudices and discriminitory practices. The civil rights movement initially gained momentum on issues relating to racism. The forced segregation of black Americans from white Americans in areas of housing, transportation, school and the work force was successfully challenged in court. In one landmark decision American courts ruled: "separate but equal is inherently unequal".[6] This ruling, and others that followed, were soon used by other groups in their battles to establish or to protect their human rights. Traditionally disenfranchised populations that became involved in the civil rights movement include the elderly, women, children, parents of children with special needs and persons with handicapping conditions themselves.

Battles in the area of civil rights fought in American law courts, have resulted in legislative change. American laws have been passed which have had significant impact on Canadian concepts regarding the rights of children and on the relationships between parents of children with special needs and professionals. For example, American Public Law 94-142, passed in 1975, guarantees education for all children. It also provides specific guidelines to include parents in decisions about their children's education. Professionals, by law, must collaborate with parents. Canadian parents and professionals are using American law and resulting changes in services in the U.S.A to encourage the passage of similar laws and changes in Canada.

The Consumer Movement [7]

Beginning in the 1950s, North America saw a growing movement for consumer rights. It emphasized the rights of consumers to seek out and choose the goods and services they felt best fitted their personal needs and desires. This trend challenged the traditional consumer-provider relationship that fostered blind faith and passivity in the consumer and bestowed magical omnipotence and paternalism on the provider.

In the field of human services, professionals began to be seen in some circumstances as consciously or unconsciously fostering dependency, passivity and learned helplessness, in their clients. Slowly, professionals began to act as consultants to their clients and programmes developed which encouraged clients to take a more active role.

Research

Since the mid-1960s, knowledge has exploded about how a person's skills and behaviours can be enhanced by changes in his environment. New teaching techniques, such as task analysis, precision teaching, and behaviour modification, have revolutionized education for children with special developmental needs. The basic belief that **all** children are capable of learning has been increasingly accepted. Parent potential and existing teaching abilities have also been acknowledged. More and more, parents are acknowledged as the primary 'teachers' of their children, and for having a significant influence on their child's development, in the way their children feel about themselves, their ability to think, communicate and get along with others.

Research has also demonstrated the advantages of **early** involvement of parents in the education and training of their children. Babies start learning from birth, if not earlier. However, infants with special needs may have difficulty in organizing and responding to information in their environment. In addition, positive patterns of interaction between parents and infants may be harder to establish because the infant's messages to the parent are weaker or less clear.

Infant programmes have been established in many communities to enable parents to learn more about encouraging their infants' development. Many of these programmes recognize parents as the primary 'teachers' of their infants and professionals act as consultants to the parent. Because professionals from different disciplines may be involved in these programmes, this has created an additional challenge; professionals must learn how to work more effectively with each other.

Research which supports the direct involvement of parents in infant development programmes has led to an examination of the parent's position during the child's pre-school years. Traditionally, distinct boundaries separated the kingdoms of parent and home from teacher and school. However, as a result of early intervention programmes, many parents saw the benefit of working, with guidance, with their infants and they began to expect on-going involvement in their children's education as they grew older.

Opportunities for continued parent involvement and training for preschool and school teachers to work with parents are now developing.

Although these social trends, or forces for change, may provide a strong rationale for closer parent-professional working relationships, good working relationships are often difficult to develop. Parents and professionals have in common a concern for the well being of the child. However, they view the child, and their role with regard to the child, from very different perspectives. For good working relationships to develop, these different roles and perspectives should be acknowledged and respected. The following sections describe some differences in roles and perspectives.

BEING A PARENT

Parents of children with special needs perform many roles. Some of these are roles expected of all parents. Some are quite specific to parents of children with special needs. In this section, we will discuss these roles and how difficult they are to balance. In particular, we will look at how some parenting roles seem to be quite stable over time and across cultures, while others are undergoing rapid change. We will also discuss some of the stressful features of being a parent, particularly of a child with special needs.

Stability...

Some aspects of parenting have persisted over the years. They apply universally to parents of all children, regardless of whether or not the children have special needs. We believe that the following statements are true of all parents:

Most parents want to be good parents. Even though they may differ in their approaches, they generally seek to do what is best for their families.

Parents have values and attitudes based on their past experiences. All new parents have positive and negative attitudes towards parenting. The ways in which we approach parenthood are influenced by the ways we were treated by our parents and families when we were children.

Parents sometimes see their children as extensions of themselves. They feel responsible for their child's behaviour. When their children misbehave or do poorly at something, they feel they have failed and, when their children do well, parents take credit for the child's accomplishment.

Parenting is never finished. The nature of its demands changes as the child grows older.

The greatest rewards of parenting are often not easily explained. They may be very simple, spontaneous things such as a little cuddle when one is feeling low or the first attempts to make you a breakfast.

Parenting is a process of letting go. Parents must learn to deal with their child's need, or demand, for increasing independence.

Parenting is different with each child. What works well with one child does not necessarily work with another child. What works well today, does not necessarily work well tomorrow with the same child.

Parents have their own needs and feelings. Sometimes being a parent helps to fulfill personal needs for love, security, personal worth and creativity. At other times, being a parent gets in the way of personal needs. Sometimes the busy-ness of parenting prevents parents from even realizing that they have needs, much less knowing what they are.

Being a parent stirs up a variety of feelings. Most parents know what it is to have feelings of happiness, sadness, joy, excitement, frustration, anger, boredom. Sometimes these emotions are direct responses to a given situation. Sometimes they reflect bottled up past reactions to the child, other family members, friends, neighbors, or work associates.

All parents need positive feedback from their children. All need to feel that they are doing a good job to feel good about themselves as parents.

Parenting involves a great deal of repetition and routine. It takes a great deal of patience. Most parents wish they had more.

...and Change

Parents living in the same time period and the same culture share many myths and assumptions about child-rearing. But these change over time as the result of new value systems, new research, and new priorities in society. Consider, for example, the stern Victorian command that children be seen and not heard. Present-day parents may occasionally resort to this, but children are generally given more opportunity to express themselves. Parents today are also aware of the contribution that environment makes to a child's cognitive and language development. Many parents worry about providing a nurturing home and appropriate toys and activities which may encourage their child's intellectual development. While this has made parents more aware of their child's phases of growth, it has also made them more anxious.

Society's expectations of mothers and fathers are less clearly defined today than in the past. Although some families continue to follow traditional models, other families are creating their own social expectations of parenthood. More and more, fathers expect to help with daily chores and to accept more responsibility in looking after their children. Many mothers, either through choice or necessity, work outside the home. Mothers at home may feel pressure to contribute financially to their household income or to develop other aspects of themselves through a second career.

However, the attitude that rearing children and maintaining a home is 'women's work' is ingrained both in our culture and in ourselves. As a result, women who work outside the home often struggle to become superwomen, keeping perfect homes, rearing faultless children and achieving careers outside the home. What a source of frustration, both for the women and their families!

Parenting today is less a private, family affair and more affected by public influences. Traditionally, the new mother looked to her mother as the authority on child rearing. With families living farther apart, grandmotherly advice at long distance is now supplemented or superceded by 'how to' experts on parenting and child development. Dr. Spock's encyclopedia of baby and child care, published in 1946, marked the beginning of widespread reliance on professional authorities. Since then, the market has been flooded and the authorities frequently disagree on solutions to parenting problems.

Assumptions that Canadian parents have in the 1980s differ from those which parents had in the past. The old maxims such as picking up a crying baby will spoil him, or a father's masculinity will be threatened if he changes diapers, have all become myths.

But, other myths linger on. We tell ourselves that other parents do a better job. Other parents don't lose their patience as much as we do. Other children don't misbehave like ours. We declare that we are directly responsible for our child's behaviour. And many parents believe that the first three years of the child's life are so critical that they can't allow themselves to make any mistakes.

Parents as Teachers

The modern parent is expected to take an active part in teaching their young children. This is particularly true of parents of children with special needs. In this role, parents have several learning tasks. These include:

Learning about their child's handicap and how to make the most of his or her abilities. This involves gathering the most recent information on the child's condition and coming to terms with what can and what cannot be changed. It will also involve understanding the child's constantly changing developmental needs and trying to make one's home a stimulating environment.

Learning how to locate appropriate community services. This involves finding out the range and quality of such services and how to involve the child in those that are appropriate. In some cases, there may not be adequate support services in the community and this often leads parents into the position of acting as an advocate for their child - sometimes at great emotional cost.

Learning how to achieve balance. Coordinating and carrying out suggestions of professionals requires parents to become something of parent-teachers. Finding the proper balance between these two roles, while balancing time with the child with special needs and the rest of the family, can be a very demanding task. "Don't ever cast yourself in the role of the well-adjusted parent. It's too much work", one wise parent has written.

Coming Out

Particularly at the time when they find that they have a child with special needs, parents are confronted, or feel confronted, with a range of social stresses. For the most part, only the parents themselves can reduce these stresses and for the most part it involves them coming out with their child into the community. This process may take several forms including:

Teaching others about children with special needs. Family, friends, neighbours, and even the community at large will need to be educated about the lives and rights of children with special needs. Parents may not have completed their own adjustment before they may be called upon to help other people adjust. To a large extent their response will set the tone for other people's reactions. This might require parents presenting a well adjusted face in public and answering comfortably and knowledgably about their children. It may involve parents taking the initiative in discussing their child's condition. As one writer said,

> *"Most of my relatives do not talk about Beckie with me; from their point of view, there is really not much to say after the initial 'too-bad-ness' has been expressed. But, since the concern and care for her goes on and on in my life, leaving the topic unmentioned is to treat a major segment of my mental and emotional life as unmentionable."* [9]

Alternately, parents are sometimes overwhelmed by the uneducated judgements of others. With good intentions, friends and family may say, "Don't worry, she'll grow out of it."

Reaching out to new parents of children with special needs. At some point, parents may want to share their experiences and the lessons they have learned with other parents of children with special needs. Many parents, too, become actively involved in parent organizations, sometimes taking an active advocacy role on behalf of all children with special needs.

Coming to Terms with Oneself

No one chooses to have a child with special needs, but the vast majority of parents eventually come to terms with their child and come to love him or her as a full member of their family. This process can take time, however, and it involves as much managing one's feelings as it does understanding the feelings of others. One parent has said:

> *"I think we should give honest and full expression to our grief. I suspect that when, in our attempts to be brave and face the future, we repress our feelings, then these feelings of pain and sorrow last longer. All I'm trying to say is that there's a time for weeping and then a time for pushing ahead, and I don't think you can do the second without going through the first."* [10]

Some parents can express feelings and learn to manage feelings with help and support from other family members, friends and the wider community circle. Others benefit from sharing their feelings and reactions with other parents of children with special needs 'who have been there.' Professional counselling may be helpful for parents who are having a particularly difficult time.

A major part of coming to terms with the reality that your child has special needs involves letting go of the fantasies that all parents have about their children's immediate and future potential. The perfect child does not exist. In coming to terms with this, parents who have children with special needs have labelled the steps they have taken to come to terms as: the glooms; the speeds; the blocks; the hurts; the guilts; the greats; the hates; and the give-ups. They overlap, but parents do come to terms with the impact of the identification and diagnosis of a special needs child. One writer has said:

> *"Accept the fact that the child of your dreams never was and never would have been. All parents have to do this sooner or later. Your problem: you must do it sooner."* [11]

UNDERSTANDING PROFESSIONALS

Just as some roles carried out by parents are fairly stable, and some have shifted over time, so too have professionals' roles. In working toward a parent-professional partnership, we believe it is very important for parents to understand something of how professionals feel and think and some of the stresses they confront in their working lives.

Stability...

Although services for children with special needs have only recently been recognized as requiring highly trained professional staff, there are several factors that professionals tend to have in common, that persist over time. Most professionals would share the following beliefs:

Working with people in a helping or advisory relationship requires specialized training. While not always practiced, professionals, as a group, believe that advanced theoretical and practical training is required to be an effective helper. The needs and problems presented by people seeking help or support are often complex.

Great care must be taken in respecting the right to privacy of clients. In dealing with clients and their families, very sensitive information is usually obtained and professionals recognize that it is essential to respect its confidentiality.

It is important to be objective in dealing with clients. Both as a need to preserve judgement and to avoid becoming too deeply emotionally involved with clients, most professionals see the need to keep some emotional distance.

...and Change

Perhaps in few other human services, professionals working with families of children with special needs are facing up to a series of rapid changes in the way in which they are expected to meet the needs of their clients. These changes include such areas as:

The shift from segregated to integrated care. No longer are persons with handicaps seen as being best provided for in institutions or in segregated schools. Instead, over the last ten years or so, there has been a rapid shift towards community care and integrated education. For professionals trained and experienced in the old systems this has meant a dramatic realignment of their roles.

A growing appreciation of clients' rights. No longer are the families of children with special needs seen as occupying a subservient, passive role in determining their children's education and care. Rather, as we mentioned earlier in this handbook, parents' rights are increasingly being recognized. So, too, are the rights of the persons with handicaps themselves. These changes, of course, have considerable effects on the way in which professionals carry out their tasks. They mean, for example, a much greater openness with parents and a 'giving up' of some of the power for decision-making.

A greater sharing of responsibility among professionals. In recent years, the idea of a professional working alone or in a particular area of expertise, oblivious to the contributions of other professionals, has almost gone by the boards. Instead, the shift has been towards a multidisciplinary style of operation in which professionals work as a team, sometimes overlapping with their colleagues. This point bears more detailed discussion so we return to it in the next section.

Coming to Terms with Working with Others

Professionals are generally educated to provide answers and find solutions for the people to whom they provide service. They are usually not well educated in helping other people find their own solutions or make their own decisions. The Chinese moral, 'Give a man a fish and he eats for one day, teach him to fish and he eats for a lifetime,' had some application here. Many professionals recognize this and wish to become more effective in sharing skills with parents.

Parents too, increasingly expect to work more closely with professionals. Because this is a relatively recent phenomenon, many professionals, and parents, do not have the training or skills to make 'partnership' work as well as they might wish. Professional training schools, in the past, did not include much information, if any, on working with parents, or the important role that parents play with regard to their child's development. Research which supports this has emerged only in the past ten years.

If training in working with parents is provided it is usually in the context of a university classroom. Theories or concepts supporting partnership may be presented but they may be hard to put into practice. Researchers and theorists often do not deal with the 'real world' and develop ideas on the basis of ideal, one to one relationships. Many professionals in practice have overwhelming case-loads, and feel frustrated by a lack of training or their inability to practice what has been preached to them.

Professionals are also expected to work well with other professionals who are involved with a child and family. Interprofessional cooperation can do much to encourage good working relationships with parents. However, professionals are not generally educated to see the connection of their specific area of expertise with other areas. Not knowing the 'how, when and whys' of referral to other professionals who might contribute to child/family development is further complicated by rapid growth in human services. New professions, new specialties within professions such as 'paediatric physiotherapy', and changes in traditional approaches are developing as our knowledge expands. This information is often not shared well within disciplines or from one discipline to another. Trying to keep well informed in a rapidly changing world with poor systems of information exchange creates stress.

'In-service', or on the job training, can help to provide professionals with skills and information they need and want. But in-service training is not always available. Some agencies who employ professionals do not see it as a priority and do not budget for it. Other agencies are so busy trying to meet the day to day needs of clients they do not make time for it. Because of the 'crises' nature of some professionals' work, in-service, if offered, may be cut short because of an emergency. In-service, is usually planned well in advance. If it conflicts with a more recently scheduled assessment or conference on a child or family, again it may be cut short or not attended.

Professionals, like parents, might wish to work in 'partnership' but may feel ill-prepared for the challenge. When we are expected to do something that we have not been trained to do, or when we question our skills to do a job well, we experience stress. This makes it even more difficult to work well together.

Professionals, Too, Face Social Pressures

We believe that the vast majority of professionals care deeply about the problems of the children with whom they work. Like parents, though, at times they feel frustrated, helpless and inadequate. Their feelings may only echo the intensity of a parent but many professionals experience emotional strain relating to a child's delay, progress, or health. As one writer said: "A child's problem and his parent's pain touch doctors and teachers deeply. They are vulnerable too." [12]

Limitations...

People who choose a career in human services generally have a genuine concern for others and an interest in providing services that will be of help to others. Most want to do a good job. Often, however, they are faced with needs that they cannot meet, or expectations they cannot fulfill. Professionals generally work long and irregular hours, sometimes sacrificing personal lives and time with their families to try to meet the needs of those they are helping. Decisions they make may have a profound impact on the lives of others. They must deal with a range of responsibilities, often with insufficient resources available to them. They are asked for cures when no cures are available. Questions are asked about a child's development but for some children, no answers can be found, or if found, are very hard to present to parents. For many parents some answers are very hard to accept.

Sometimes, parents do not have realistic expectations of what professionals can or cannot do, should or should not do. Even when these are discussed, parents may find it difficult to respect limitations. Professionals, in some senses trained to be 'selfless', also find it difficult to set limits or to abide by them. "No more than two evening meetings per week so I can take my son to hockey", is hard to

remember if you are faced with an urgent request to attend a third 'special' meeting in one week. Although professionals may overbook themselves in daily practice, parents as well may stay longer than a set appointment time or arrive late and create a scheduling problem for other parents.

...and Prejudices

Professionals face the same prejudices that parents face in this society. People - children and adults - who have special developmental needs are devalued. Although we have come a very long way in changing attitudes and in providing services, prejudice exists and many services are inadequate. Professionals face colleagues who do not believe that people with handicaps have the same rights as others. A special education teacher may want to provide opportunities for integration but finds that the regular classroom, next door, is closed. A doctor may refer a child to an eye specialist, but is told the child is retarded, he doesn't need glasses. It is not just parents who face boundaries set up to exclude children with special needs.

These prejudices also affect how society perceives professionals who work with children with special developmental needs. ''You must be very patient, caring, loving, dedicated, selfless, etc., to work with 'the handicapped'.'' These are common comments. There is something in the mythology of handicaps that affects us all. It is by 'charity' not 'right' that many services are developed and funded, and some professionals who choose this field are considered to have more 'Christian' ideals than professionals in other human services. Colleagues, as well as the general public, hold these views. These views devalue the child, the parent, and the professional who works with them.

Many organizations employing professionals continue to rely on the 'charity' image to raise funds, and to gain volunteer support. Telethons, bingo drives, public fund raising campaigns, portray ''poor unfortunate'' children and their families. Professionals wishing to foster pride and independence in these families are caught in the middle. This is further complicated by the fact that many of these agencies are governed by parent boards. So professionals who wish to challenge images of 'helplessness' in children and their parents must challenge other parents to do this.

Many agencies who employ professionals today, were originally staffed solely by untrained volunteers who worked for nothing, and put in long hours under poor working conditions. Professionals hired by these agencies are sometimes expected to carry on this 'grand' tradition. Many do. Although they are paid for their work, there are often considerable discrepancies in terms of salary, benefits and working conditions, that compare most unfavourably with colleagues who work with 'typical' children and their families. This furthers the 'selfless and dedicated' myth that reinforces our perceptions of children with special needs as being less than entitled to the best paid professional assistance available.

Professionals may have misconceptions about parents

Although there is little available to help professionals work in partnership with parents, some professional literature makes generalizations about parents that suggest 'partnership' is not a feasible concept. A special 'psychology of exceptional parents' has been created, some of which tends to segregate parents into 'like' groups much as their sons and daughters have been labelled and segregated. Rooted firmly in this literature are many negative connotations.

Some of this literature has described parents as likely to be: over-protective of the child; manifesting severe depression; unable to accept the child as having special needs; experiencing marriage breakdown and focusing irrational hostility on a professional. Needless to say, professionals who expect parents to behave in some or all of the above ways will find it difficult to work well with parents. They may feel that their contribution to a child's development is significantly greater than the parents. They may feel uncomfortable in sharing information or skills because they do not respect the parent's ability to carry them out. And they may not trust parents to be able to make good decisions about their child. Because of this, a professional may view him or herself as an adversary rather than as an ally, in competition for the child. On the other hand, concerned professionals may view themselves as the child's best advocate, rather than the parents.

Relationships may be further strained because professionals themselves expect and are often expected by parents, to be in control - knowledgable decision makers. This creates a two way phenomenon. Some professionals believe themselves to be all knowing and powerful. Some parents believe themselves to be passive, dependent, and helpless. This active-passive model makes it hard to share authority and control, without both sides feeling confused, threatened and inadequate.

"The disease of professionals is that we believe that we are too good for the illness and problems with which we are required to deal. The disease of consumers is that they believe us, that they refuse to remember that people are people, that we are all in need of something and someone." [13]

SIMILAR CONCERNS, DIFFERENT PERSPECTIVES

"Experience sets parents and professionals apart from one another." [14]

While parents and professionals both care about children, they view them from different perspectives. On the one hand, it could be said that parents care intensely, and at times irrationally, about their child in ways that cannot be matched by others. No one can or will feel as responsible for the general well-being of their child. Although parents must make decisions about their child as objectively as possible, by nature they view him/her emotionally. This 'emotionality' is the 'tie that binds' and sustains parents through difficult periods of parenting. The roles and responsibilities of parents are limitless and timeless. The needs of their child must be balanced against the needs of other family members.

Professionals, on the other hand, are trained to view a child from a clinical perspective. They may care deeply about a child but are expected to maintain a distance that allows them to view the child with objectivity. Their responsibilities are defined in terms of how and when they are involved. In many cases the child is seen outside the family context, and the needs of the child may be balanced against the needs of other children to whom they are providing service.

Although the roles are very different, parents and professionals share common 'people needs'. These needs sometimes lead to competition, even conflict. These needs include power, respect, and self-confidence. Power relates to the feeling that we have control over important parts of our life; respect means that others value us and self-confidence comes from the feeling that we are capable and successful in our endeavours. For a number of reasons, these needs are usually acknowledged and met more easily for professionals than for parents. For both to work well together, however, this imbalance must be recognized and resolved.

Power

"The relationship between parents of disabled children and professionals is imbalanced. An individual family needs a professional far more than the professional needs them. The professional, particularly if he is a doctor enjoys a higher status than a parent. [Parenthood, alas, confers negative status; only professional training or irrelevant social factors raise the parent to the professional level]. In consequence of these asymmetries of need and prestige, the professional wields far more power than the parent." [15]

Professionals generally choose their careers and must study in formal training programmes as preparation for their work. They are expected to be knowledgeable in their field of expertise and are paid in acordance (generally) with their training and work experience. The ability to choose a career, or to change a career, to have information that others do not have, and to be paid for work, are factors which give power to professionals that parents do not have.

Parenthood may be planned or unplanned but it is generally not by choice that parents have a child with special needs. Parents do not have special training to prepare them for parenthood. The training is on the job. The immediate rewards are not monetary, they are intangible. Parents have limited choices, they cannot 'choose' or 'change' their children; they have more difficulty in accessing information and the work is 'voluntary'.

Professionals have status and power that parents do not have, and parents of children with special needs, who must seek support and information from strangers, may feel even less 'powerful' than other parents. Integral to this is concern for the child and the vulnerability that parents feel when a child has a handicap.

> *"We are painfully reminded that our most precious possessions, our dearest dreams can be completely destroyed and that we are totally helpless to do anything about it."* [16]

Respect

> *"In general, the more difficult, time consuming and expensive the rites of passage and the more mysterious the vocabulary, the more respect the professional can command."* [17]

Professionals generally receive formal recognition for their training and for work well done. Ability in school or on the job is measured. Scholarships, diplomas, degrees, evaluation, salary raises and occasionally professional accolades, or awards, are ways we acknowledge and respect professional competance. As well, clients and colleagues provide informal feedback on work well done. These acknowledgements contribute to an attitude that makes it difficult to appreciate and respect the contributions of others.

On the other hand,

> *"The exceptional family stands in a strange, and at times rather sad relationship to outside opinion. Guilty, unsure, unprepared and lonely, both parents and children long for understanding, reassurance and approval."* [18]

Parents are far more likely to be criticized than commended, disregarded than respected. In interacting with professionals, parents may have difficulty keeping their sense of self-respect and confidence. The actual act of asking for help can intimidate even the most confident and capable person. When asking for support, parents are seldom given recognition for what they have accomplished with their child. If asked by a professional for their opinion, their observations about their child may be doubted. That children behave quite differently in strange settings, especially if they have travelled miles for an appointment, is often forgotten. Their child may be treated as less than deserving of services available for other children. As a result, parents may become self-effacing and have trouble expressing their point of view. Even the normal supports of family, friends, and neighbours may react in ways that diminish parental pride and feelings of respect. That a hard job has been done well is rarely acknowledged to parents.

Self-Confidence

> *"It often looks to parents as though outsiders hold the child's future in their hands. For their part, professionals often feel far less powerful than they appear to clients."* [19]

We generally feel self-confident when we are doing something that we know how to do and when the product of our labours is successful. Although professionals may feel frustrated and inadequate, in certain circumstances, this is usually a dimmer echo to what parents experience.

For a professional, failure to bring positive changes to a child and family, may be balanced by successful experiences with another family. A professional as well, can rightly or wrongly, attribute failure of professional approaches to other factors such as the child's handicap, or a parent's lack of follow-through. Professionals are expected to feel confident and to project 'competence'. This expectation and the fact that they have a range of responsibilities, many bringing degrees of success, contributes to the imbalance between themselves and parents.

Self-confidence for parents is greatly influenced by their relationships with their child. "Our children are our achievements."[20] How well parents meet their child's needs, how much control they feel they have over their child's behaviour and development, and how well their child does, gives parents confidence that they are doing well as a parent. Regardless of how well children do, however, most parents have feelings of inadequacy or have doubts about their abilities. Consider, this quote for example:

> *"Has this ever happened to you? You read a book or magazine article on family life, and you end up feeling your family is a bit inadequate. You listen to someone lecture on the healthy family and you come away feeling you are failures as moms and dads because your family doesn't seem to measure up to what the lecturer describes."* [21]

For parents of children with special needs, self-confidence may be truly threatened:

> *"When adults care for an infant whose signals are difficult to read, who is unpredictable and/or unresponsive, they can quickly come to feel incompetent, frustrated and helpless."* [22]

Children with special needs may not present clear messages or consistent messages to parents. Sleep and feeding patterns may not stabilize easily and parents may have problems in knowing how best to meet the day to day needs of their child. Sometimes it is hard to tell what is 'normal' behaviour in the infant and what might be a result or effect of a developmental problem. If parents feel 'out of touch' with their child and have doubts and fears about how they will manage, self-confidence can be truly undermined.

Each of us needs to feel in control, that we are valued by others and that we are capable of managing our lives and families. Good working relationships between parents and professionals are easier to develop when each recognizes and respects the other's needs.

As we have pointed out, these relationships by their nature are 'imbalanced'. The 'people needs' of professionals are far more easily met than are the 'people needs' of parents. Therefore, it is much more the responsibility of professionals to attempt to correct the imbalance than it is for parents. Both however, must work at this and the following lists of obstacles and solutions summarize areas needing consideration.

WORKING TOGETHER

As we have indicated in the previous section, parents and professionals share similar concerns, yet have different perspectives, priorities and pressures. These similarities and differences pose unique challenges to them when they wish to form closer working relationships. Some obstacles to partnership are summarized as follows:

Obstacles

Professionals:

- no preparation or previous experience in working with parents
- anxiety and/or resistance to the prospect of parent involvement
- a tendency to adopt an authoritarian approach to parents
- uncertainty about admitting limitations in knowledge or skills, and/or not referring on to others
- limited understanding of the range of differences from one family to another in terms of life skills, abilities, priorities or restraints
- expecting too much or too little from parents
- not taking parents' concerns seriously. Adopting a 'wait and see' attitude
- withholding information, or refusing access to information
- using professional jargon
- emphasizing weaknesses in child and family and not acknowledging strengths

For Parents

- lack of confidence in themselves as parents
- negative past experiences with professionals
- problems in balancing the demands of the child with special needs and the needs of other family members
- under- or over-estimating their child's potential
- under- or over-estimating the contribution professionals can make
- coping with the demands placed on them by professionals

Solutions

Parents we have spoken to feel that obstacles such as those just outlined could be removed if professionals and parents paid heed to the following points:

For Professionals

- give parents recognition for their strengths and successes
- tell parents they are experts, too, through specific and accurate comments
- do not patronize
- believe the parent; children do act differently in different settings
- show respect for children and value them as persons
- accept peoples' right to be different, avoid generalizing and stereotyping
- listen to parents; sometimes they know more than you
- ask for parents' opinions, then show you value them
- do not pressure parents to participate

For Parents

- don't be afraid to ask for help
- ask for clarification if information given is not clear to you
- challenge professionals if you disagree
- be honest about home happenings; explain practical restrictions on time and energy
- seek other kinds of help if you need it
- if you are not pleased with professionals' advice or treatment, tell them
- show your appreciation for good service and attitude

Parents and professionals, working together toward mutual goals, in 'partnership', is a relatively new approach to an old relationship. As a new approach, like other trends in society, it runs the risk of misinterpretation, over-utilization, and creating unreal expectations or a magic cure, or panacea.

'Normalization' has had a similar history of misinterpretation. Like normalization, partnership should be understood as a process or concept that can alter our perceptions and actions, and has the potential to benefit children. The following describes current 'myths' and 'realities' surrounding 'partnership'.

Myths and Realities

For those parents and professionals contemplating working together, there are several myths which we feel should be addressed.

Myth	Partnership is a regular part of services for children with special needs.
Reality	While it is among the leading changes anticipated in North America, partnership is not fully understood or accepted by many service providers or parents.
Myth	All professional/parent relationships should have partnership as a goal.
Reality	Many parent/professional contacts, particularly those of a short-term or acute nature, do not require partnership. A service is needed, rendered and the transaction completed, with both parties satisfied. Either side may have some of the rights of partnership in these encounters, however.
Myth	Partnership means either the parent is cajoled into accepting professional expertise or the professional is pressured into relinquishing some responsibility and control.
Reality	Both the parent and the professional must recognize and respect the unique contributions each can make to the child's welfare.
Myth	For every family, the more parent involvement the better.
Reality	The amount of involvement which is beneficial varies tremendously from family to family. It varies, as well, in one family over time. Parents should be permitted to choose from several options for involvement, what suits them best. Parents should not be made to feel guilty if their time and energy limits their involvement.
Myth	There is only one right pathway to partnership.
Reality	Partnership is a different process for every parent/professional relationship.
Myth	A partnership relationship remains the same over time.
Reality	Partnership should not be looked on as fixed and unchanging. It is a process in constant motion.
Myth	Partnership is easy.
Reality	Good intentions are only a beginning. Expect to work hard to develop and maintain this relationship.

Checklists

There are no simple recipes for creating good working relationships between parents and professionals. These checklists are included to illustrate good practices for personal encounters or for programmes which serve children with special needs and their families. Not every practice listed could be achieved by an individual or by a programme but, in total, represent an 'ideal'. They may help you to select the programme best suited for your child and family. As well, if you are involved in running or monitoring a programme, they may be used to guide change over time.

Some checklists were developed especially for this book, while others were adapted from other sources.

Features that Contribute to Positive Parent/Professional Interaction in a Birth Hospital

The arrival of a new baby into a family precipitates a range of major physical, mental and emotional responses in parents. If a newly born infant is suspected or known to have a handicap, this adds a tremendous impact to an already emotionally heightened experience. Informed counselling during and following the diagnosis may lessen this impact. More importantly, it can serve to set the stage for on-going positive parent/professional relationships.

1. The maternity unit has written general guidelines on communicating with parents of a newly born infant suspected or known to have a handicap.

2. These guidelines were developed in consultation with hospital physicians, maternity nurses, social workers and parent representatives of local or provincial parent organizations.

3. The hospital board has approved these guidelines and developed means to ensure they are carried out.

4. These guidelines specify:

    - Who informs the parents
    - Both parents be present (if possible)
    - The baby be present (if possible)
    - The interview is done in private
    - The physician is of sufficient seniority that he/she has had experience with this situation and knowledge of handicapping conditions
    - More specialist advice will be sought, if necessary

5. The physician informing the parents about the baby's handicap is knowledgable about infant programmes, family support programmes, and parent organizations which may benefit the family, and he/she will initiate referral to appropriate services.

6. Parents are encouraged to meet the physician on more than one occasion to discuss further questions or concerns.

7. Parents who suspect there is something wrong before they have been told the child has a handicap, are not given untruthful reassurances, but are given an honest answer as soon as possible.

8. Parents are given the privacy as a couple which they may need, yet are not made to feel ostracized from others in the maternity unit.

9. Community professionals and/or representatives of a parent organization are welcome to visit the new parents in the birth hospital, if the parents consent to this.

10. Guidelines as described above are reviewed regularly to ensure new parents are given verbal and written, up-to-date information on the handicap and on community resources; and encouraged to make contact with these resources at the earliest opportunity.

Options for Parent Involvement in Early Childhood Services

The following checklist lists different ways in which parents are presently involved in services for their child. No parent would wish to be or need to be involved at every level listed here. However, you may use this to give you ideas about ways that you could participate. If your child is enrolled in a programme and you wish to become more involved, this checklist could be used in discussion with the professionals involved in the service to focus on ways you might participate more fully.

	YES	NO	UNCERTAIN
1. RECEIVING SERVICES-What do you want from the agency or professional?			
General Information			
Assessment or Diagnostic Information			
Services for Your Child, which do not require your participation, e.g.			
. Therapy.			
. Swimming			
. Play Group			
. Respite Care			
. Other_____			
2. INCREASING YOUR KNOWLEDGE - What specific information do you need?			
Child Development and Family Relationships			
. Normal Growth and Development in Early Childhood			
. Principles Influencing Normal Child Development.			
. Individual Differences in Children . .			
. Parent-Infant Relationships.			
. Common Features of Relationships with Siblings and Grandparents			
. Role of Play in Development			
. Nutrition			
. Other_____			

	YES	NO	UNCERTAIN
Issues related to Special Developmental Needs, such as:			
. Handicapping Conditions			
. How Other Families Manage			
. Community Resources: Availability and How to Locate			
. Assessments: Purpose and Procedures			
. Contact with Other Parents			
. Medications: Purposes, Side Effects and Precautions			
. Other _____			
Adapting Your Home to Meet Your Child's Needs:			
. Learning the Best Positions for Your Child			
. Learning How to Carry and Handle Your Child			
. Learning to Use Adaptive Equipment			
. Choosing Toys and Activities Best Suited to Your Child's Age			
. Encouraging Positive Play Experiences . .			
. Other _____			
Becoming a more Effective Teacher of Your Child by Learning:			
. Principles of Behaviour Management			
. Recording Child's Progress			
. Structuring and Maintaining Teaching Sessions			
. Other _____			

	YES	NO	UNCERTAIN
3. PROVIDING INPUT INTO PROGRAMME DEVELOPMENT FOR YOUR CHILD			
What information can you contribute about:			
Your Child			
. Child's Behaviour in Different Situations			
. Child's Needs.			
. Child's Strengths.			
. Child's Weaknesses			
. Likes and Dislikes			
. Temperament			
. Relationships with Family Members and Others			
Your Concerns and Priorities			
Your Available Time in Relation to Your Family . . .			
Ongoing Feedback to Professionals			
4. SHARING THE PROCESS OF DECISION MAKING AND POLICY DEVELOPMENT			
Would you be interested in serving as:			
A Board Member of a Service Agency			
A Policy Maker at:			
. Local Level			
. Provincial Level			
. National Level			
A Lobbyist for:			
. Increased Funding			
. New Programmes and Support Services			
. Children's Rights			
. Service Accountability			
An Advocate for:			
. Accessibility of Services			
. Availability of Appropriate Services			
. Other _____			

Professional Attitudes and Practices that Encourage Confidence in the Parenting Role [3]

An increasing number of programmes provide parents with information and support in the parent's home. Although the 'home' should be the place where professional and parent 'barriers' are least felt, this is not always the case. It is almost as easy for professionals to be as instructive and "bossy" in a home as it is in a clinic or hospital setting. These points may help you and your home visitor to examine your relationship and to function more effectively together.

	Some-times	Always	Never
1. Do I feel in control of the visits in terms of . what happens to my child . . . . what I am doing?			
2. Although professionals may provide significant information and skills, do they listen to me and respect the fact that I know my child far better than they do?			
3. Do I trust the professional to understand and respond to my needs and priorities?			
4. Do professionals recognize my strengths and try to build on them?			
5. Do professionals help me . to set priorities for my child . . . . . put these goals and priorities into daily practice?			
6. Am I as involved as the professional in planning activities for my child?			
7. Do professionals recognize . the individuality of my interaction with my child . . . . build on those activities we enjoy together?			
8. Do professionals tell me "why" and "how" the activities I am doing with my child benefit him/her?			
9. Do professionals give me alternate ways to deal with my child so that I don't feel a sense of failure if something doesn't work?			
10. If my child is particularly unresponsive, do professionals help me deal with this frustration?			

Parent Questionnaire
for Monitoring Home Based Programmes

This questionnaire was developed by parents and professionals involved in an Infant Development Programme serving children aged birth to three years. It is sent to all families receiving services from the programme on an annual basis.

Questionnaires such as this enable parents and professionals to review services, to make changes if necessary and to reinforce staff for doing a good job. For individual parents it allows regular opportunities to express satisfaction or concerns about a programme.

KEY: S.D. = Strongly Disagree S.A. = Strongly Agree
D. = Disagree A. = Agree
(Please use space provided after each question for comments)

SA	A	SD	D

1. I have found this programme useful in learning new ways of helping my child. COMMENTS: _____

2. I am receiving a sufficient number of visits from my Infant Development Consultant. COMMENTS: _____

3. The Infant Development Consultant attempts to include other members of the family during her visits. COMMENTS: _____

4. I feel the Infant Development Consultant could be more supportive in helping me handle my feelings as the parent of a delayed infant. COMMENTS: _____

5. I feel that I am now more aware of the resources available for my child, now and in the future. COMMENTS: _____

	SA	A	SD	D
6. My Infant Development Consultant regularly provides me with written descriptions of activities, as discussed during the visits, and assessment reports. COMMENTS: _____				
7. I would like the Infant Development Consultant and/or Programme Consultants to spend more time observing me working with my child, to be sure the activities are being carried out correctly. COMMENTS: _____				
8. I feel confident that the assessments used reflect my child's abilities, and form a solid basis for planning programme activities. COMMENTS: _____				
9. I would prefer more detailed instructions for working with my child, for example how many times to perform an activity, or for how long. COMMENTS: _____				
10. The length of the visits is adequate. COMMENTS: _____				
11. My Infant Development Consultant tries to plan his/her visits when my child is well rested and alert. COMMENTS: _____				
12. I find the meetings with other parents both useful and supportive. COMMENTS: _____				

	SA	A	SD	D
13. I feel that I am a full partner with my Infant Development Consultant in planning my child's activities. COMMENTS: ___				
14. I would like to help in planning parent meetings and committees. COMMENTS: _____				
15. I believe I am the person most capable of bringing about change in my child's development. COMMENTS: _____				
16. With the help of the programme, I feel more accepting of my infant's difficulties. COMMENTS: _____				
17. With the help of the programme, I feel more relaxed and capable of coping with him/her. COMMENTS: _____				
18. I do not feel that I can do a good job in teaching my child because I do not have professional training in the field. COMMENTS: _____				
19. I trust my Infant Development Consultant to treat my family's problems as confidential. COMMENTS: _____				

	SA	A	SD	D
20. I do not feel I have had adequate opportunity to meet other parents with similar concerns. COMMENTS: _____				
21. I would like more information on subjects related to my child's problems (lectures, films, etc.). COMMENTS: _____				
22. I would find it helpful to have some kind of check-list or form on which to record my child's day-to-day activities and changes between visits. COMMENTS: _____				
23. I feel confident that my Infant Development Consultant is capable of interpreting the advice of the Programme Consultants (P.T., Speech, Public Health Personnel) in developing my child's programme. COMMENTS: _____				
24. I find it a terrible effort to work with my child every day. COMMENTS: _____				
25. I have been pleased with the information, books and toys provided. COMMENTS: _____				
26. I worry about what will happen to my child when he/she is age three and too old for the Infant Development Programme. COMMENTS: _____				

	SA	A	SD	D
27. I feel that the provision of a developmental programme at this stage has had a positive effect on my child's development. COMMENTS: _____				

My relation to the child is: Mother _____

Father _____

Other _____

I have been involved in the Infant Development Programme for _____ months.

Age of child at referral _____

Reason for referral _____.

Signature _____

(Please omit signature if you wish your reply to remain anonymous)

Please add any additional comments: _____

My Infant Development Consultant visits me _____ times a month, on the average.

Features that Encourage Partnership in Transition from One Programme to Another

When your child has been involved with a programme for some time you may find it quite difficult when it becomes necessary for your child to move into another programme. Programme changes usually occur when a child reaches a certain age such as three, and moves from an Infant Development Programme into a pre-school. It may also happen if your family moves or a more appropriate service becomes available.

Parents have said how hard it is to leave a programme for some of the following reasons: they have a close and understanding relationship with the current staff; the child enjoys the programme and is doing well. Because the known is generally more comfortable than the unknown, it is very reasonable to feel anxious when programme changes are necessary.

However, good preparation for a programme change can do much to relieve anxiety and to help you feel more positive about the future. The following checklist may help you identify, with current programme staff, ways to make the transition easier to handle, and more productive for all involved.

	YES	NO
1. PREPARATION FOR TRANSITION:		
. Have current staff encouraged me to look beyond their programme to future alternatives?		
. Is a range of alternatives identified for me, (e.g. different preschool programmes, primary classes)?		
. Have specific features of these programmes been clearly described?		
. Am I encouraged to tour these programmes?		
. Are current staff prepared to help me make a decision and negotiate with the programme choices?		
. Are current staff supportive of my decision?		
. Are current staff supportive of the new programmes and personnel?		
. Is there a current, up-to-date report on my child on which decisions can be based?		
2. SUMMARY REPORT WHEN CHILD LEAVES A PROGRAMME		
. If this report is not addressed to me, do I receive a copy of it?		
. Do I have a say over who receives this report?		
. Do all current, relevant professionals involved with my child have the opportunity to contribute to it?		

	YES	NO
. Are my needs, priorities and observations for my child incorporated into the report?		
. If contradictory assessments or information is presented, do the current staff have methods to deal with this?		
. If I disagree with aspects of this report, is this acknowledged and respected and noted?		
3. CURRENT STAFF/PARENT/NEW STAFF COMMUNICATION		
. Is it made clear who is responsible for coordinating the transition?		
. Are there opportunities for current staff, new staff and myself to meet?		
. Are other relevant professionals invited to attend?		
. Do I participate in deciding who should attend?		
. Is there opportunity for new staff to make a home visit prior to my child entering the new programme?		
. Am I invited to observe, over time, the new programme prior to my child's entry?		
. Are my needs and priorities for my child respected by the new programme staff?		
. Are my options for involvement in the new programme clearly described to me?		
4. FOLLOW UP		
. Do former staff continue, if necessary, contact with new programmes to ensure appropriate placement?		
. Are former staff available for consultation if problems arise?		
. Am I invited to continue to observe my child in the new programme?		

Preparing for a Conference

During the course of your child's involvement in an education programme or at a time when your child is leaving one programme to enter another (eg. pre-school into the school system), formal interviews, conferences, or screenings will probably be set up. Important decisions regarding educational programming or future placement are often made during the course of the interview based on the information presented by professionals involved in the programme. Consultants to the programme and programme administrators may also take part and make decisions.

If you have not had as much experience as a professional in participating in conferences, you may feel awkward, nervous, or intimidated by this meeting. Most parents have expressed these feelings about conferences, at one time or another. Because these feelings may undermine your self-confidence and therefore limit your effectiveness in dealing with the issues and decisions regarding your child, preparation for these conferences may be of benefit to you. Other parents have identified and utilized the following strategies in preparing for and attending a conference or screening.

TO PREPARE FOR A CONFERENCE

1. If at all possible both parents should attend conferences. If necessary, request the conference to be scheduled for a time that enables working parents to attend.

2. Be clear about the purpose of the meeting and decisions that will be made.

3. Find out who will be attending and how much contact time they had with your child.

4. Do you know, and work cooperatively with at least one of the professionals attending? Will they offer support to you during this meeting?

5. If you are uncertain whether or not you will receive professional support during this meeting,and/or if you feel a little insecure about your ability to present your child's case:

    a) Invite a professional who knows you and your child well to attend with you, and/or

    b) Invite a parent advocate who has had successful experiences in conferences of this nature. This person may be involved with:

        . Education Committee in a Local AMR

        . Hired Parent Advocate through an AMR or other agency.

6. Prior to the meeting, both you and the professional and/or parent advocate should:

   a) Inform the chairperson in advance who will be attending.

   b) Clarify purpose of meeting.

   c) Decide what materials (if any) to bring.

   d) Determine what questions should be asked and what information you wish to give:

      . About your Child

      . About the present or future programme

      . About available support services

      . About your expectations

DURING THE CONFERENCE

A. Your body language will convey a positive message if you:

   . Sit down in a relaxed, business-like manner.

   . Keep eye contact with people you are addressing.

   . Take the initiative in greeting others and in opening conversations.

   . Dress appropriately.

   . Don't physically isolate yourself at the table.

   . Voice your opinion when necessary.

   . Carry a folder or briefcase with your materials - organize them in front of you, so they are handy.

   . Take careful notes.

B. Your Advocate during this meeting can help you by:

   . Asking you questions.

   . Backing up your points.

   . Taking notes.

   . Making sure that information presented by professionals is clear and understood by you.

   . Reiterating decisions made at the end of the meeting, if this is not done by you or the chairman.

FOLLOWING THE MEETING

Write a letter to the chairman of the meeting outlining your understanding of:

- Major points covered.
- Decisions made. Indicate whether you are or are not in agreement.
- Dates set for accomplishment of tasks (if any).
- Your future role or responsibilities if designated.

Sometimes it might be helpful to ask for confirmation in writing or clarification of some points discussed.

CHOOSING A GROUP SETTING FOR YOUR CHILD

In the past, most pre-school programmes provided for children with special needs were segregated. However, opportunities for the integration of young children with special needs into regular pre-school programmes are increasing and some formerly segregated pre-schools are beginning to integrate typical children into their programmes. Integration has many benefits for children and their parents. Integration during the early years can do much to prepare children for continued involvement with both handicapped and non-handicapped peers, in school and in the larger community. For children to benefit fully however, professionals, in particular pre-school staff, and parents must ensure that the special needs of the child are met, whether the child is in a segregated or integrated setting. Although it may be more challenging to meet a child's special needs in a regular pre-school, it can be done, and is being done in many settings across Canada. Parent and professional 'partnership' is of particular importance in deciding what would be a good pre-school setting for a child and in balancing home/school learning environments.

The following checklists list features that should be considered when parents are looking for a pre-school placement. Typically, this is done when a child approaches his/her third birthday although some pre-schools may accept younger children. The first checklist describes features that <u>any</u> good pre-school should have, regardless of whether it is segregated or integrated. The second lists features of <u>particular</u> importance for children with <u>special needs</u>, and includes issues relevant to parent participation in the home and in the school.

What to Look for When Choosing a Group Setting for Your Child

A. THE STAFF (Teacher, Caregiver, etc.)

Competent staff should be: warm and responsive with children; encouraging of intellectual growth and development; respectful of the child's individual needs; able to cope with the demands of caring for children; consistent and fair in disciplining them.

	SOME-TIMES	ALWAYS	NEVER
1. Do the staff smile and look directly at the children when talking with them, establishing eye-to-eye contact?			
2. Do the staff appear to be physically relaxed with the children when touching, talking with or approaching them?			
3. Do the children appear to trust the staff and freely turn to them for help, information and comfort?			
4. Where do the staff appear to spend most of their time -			
. working with children			
. arranging materials			
. talking with staff in the programme?			
5. Do the staff guide children in using toys, material or equipment?			
6. Do the staff ask children yes or no questions more often than questions that require creative thoughtful, or imaginative answers which stimulate children's language and thought?			
7. Do the staff give the children enough time to respond to a question?			

	SOME-TIMES	ALWAYS	NEVER
8. Do the staff allow/encourage decision making by the children?			
9. Do the staff have a set routine or schedule organized for the children?			
. Are you pleased with the schedule?			
. Does the routine allow for a variety of needs to be met?			
10. Do the staff's expectations and treatment differ for girls and for boys?			
11. Do the staff label children or gossip about their families?			
12. Do you think the staff will be able to meet the special needs of your child? e.g. individual educational programmes, assessments, utilization of available resources (e.g. physiotherapy).			
13. Do the staff seem to be easily hassled if things are not going right?			
14. Do the staff reward and discipline a child?			
. Are you comfortable with these methods?			
. Are they consistent with your own?			
. Are expectations realistic for the developmental age of the child?			
15. Is the staff's talk with the children heavily sprinkled with DOs and DON'Ts ?			
16. Do the staff immediately mediate potentially explosive situations such as fights over toys, name calling, or physical aggressiveness?			

B. THE ENVIRONMENT

A programme's environment includes both the interactions of people and the arrangement and organization of space and materials.

	SOME-TIMES	ALWAYS	NEVER
1. Are there too many children in the group?			
2. Do the children appear to be comfortable and free with other children in the group?			
. Or are there numerous fights and disturbances?			
3. Do the children encourage one another, appear to play well with others in the group, work cooperatively among themselves?			
4. Small groups and/or individual adult attention are very important to young children.			
. Are there enough qualified people so that the individual needs of your child will be met?			
5. Check the following physical features:			
. No sharp edges on furniture			
. Wall plugs covered, and extension cords not overloaded			
. Detergents, medications and sharp instruments out of reach? Ask!			
. Stairs and low windows adequately protected?			
. Sufficient lighting and adequate cleanliness			
. Outside play areas safe from traffic.			
. Do staff have basic knowledge of first aid? (CPR)			
. Are there procedures for emergencies?			
6. Is there enough space for the number of children? Is it divided? Is there an outdoor play area?			
7. Is furniture and equipment arranged in such a manner that your child can crawl, walk, and explore freely?			

	SOMETIMES	ALWAYS	NEVER
8. Are there spaces in the setting for children to work or play quietly and actively with materials and equipment? A variety of needs being met at the same time?			
9. Are there adequate areas and facilities for children to rest and sleep?			
10. Are there special areas for a variety of activities blocks, reading, dress up, arts and crafts? Are the potentially noisy and active areas - blocks, jungle gyms, house-keeping corner - separated physically from quiet areas - reading, puzzles, art centres?			
11. Sufficiency of materials.			
. Are there adequate materials to satisfy the needs of the group?			
. Do you notice a large number of children struggling for the same materials or having to wait more than five minutes to use them?			
12. Variety			
. Are there toys and materials for activity times (hoops, balls, wagons, trikes, large climbing blocks)?			
. Quiet times (puzzles, trucks, dolls) and shaping materials (clay and blocks)?			
13. Accessibility and organization of materials.			
. Are the toys and materials within easy reach of the children?			
. Are the materials neatly arranged so children can tell where things are located and what is available for them to use?			

C. DANGER SIGNS

Any of these signals should alert you to possible serious problems.

1. You are not asked to visit the programme or encouraged to ask specific questions about what your child will do during the day. You need to observe in a programme several times before you have an accurate notion of what is going on.

2. The children move about the programme without any guidance from the adult for thirty (30) minutes or more: They have no apparent involvement with anything or anyone.

3. The staff does not respond to the children. They look past them when talking to them and give the general impression of not caring about or responding to children's presence.

4. The staffs' voices often sound angry or cross.

5. The staff seem overwhelmed with the work and responsibility of caring for children.

6. The staff are physically rough and abuse the children.

7. The centre is dirty and/or unsafe. The staff are messy or sloppy in physical appearance.

8. Your child appears unhappy and suddenly doesn't seem to be eating or sleeping well and doesn't have much enthusiasm for playing with you, other children and his/her toys. Your child may be reluctant or refuse to go to school.

Areas of Particular Importance - Special Needs

	YES	NO
SCHOOL PHILOSOPHY		
The board, staff, parents and volunteers at the preschool believe that:		
. children with special needs are children first and that opportunities for learning should be available for all children		
. children with special needs, regardless of the severity of handicap, have the potential to benefit from developmental activities		
. children with special needs benefit from interaction with non-handicapped peers		
. the family is the main support and advocate for the child and their needs and priorities must be recognized and respected		
ACCESSIBILITY		
The preschool is close to our home		
. within walking distance		
. within a 10 - 15 minute drive		
If I cannot take my child to preschool, the school facilitates the coordination of		
. parent car pools		
. volunteer drivers		
. school bus		
The preschool is physically accessible		
. few or no steps		
. washrooms close to classroom		
. suitable classroom/playground equipment and toys		
Hours of operation of preschool are convenient and/or flexible enough		
. for my child to attend		
. for me to observe and participate		
. for me to attend meetings with teachers and other staff		
. for my child's consultant (e.g. physiotherapist) to participate		

PARENT INVOLVEMENT

	YES	NO
My priorities for my child's educational needs are incorporated into the preschool setting		
. staff have a regular and formal system to set goals for preschool activities		
. I participate in setting these goals		
. a structure exists to resolve differences of opinion		
I am assisted in providing home activities for my child		
. the school communicates regularly with me regarding my child's development by		
. daily 'lunch bucket' notes		
. informal but regular talks with the teacher		
. formal weekly or monthly meetings		
. written reports on my child		
. staff are willing to share teaching strategies with me and to help me plan a home programme		
. staff are available to visit me in my home to observe and to offer suggestions when necessary for home activities		
I have opportunities to acquire information and skills that may benefit my child		
. the preschool provides parent education workshops which focus on priorities set by parents		
. the preschool encourages parents to attend educational programmes sponsored by other agencies		
I have a range of opportunities to participate in the preschool programme		
. to observe my child in the classroom		
. to volunteer as an aide in the classroom or in other preschool activities		
. to establish, review and monitor preschool policies		
. to participate in ongoing evaluation relating to staff and preschool programme		

	YES	NO
STAFF TRAINING		
Staff have thorough knowledge of normal growth and development in young children		
Staff have the qualifications and skills to meet my child's special needs and/or are willing to access resources to assist us in developing a programme		
Staff encourage the involvement of community resources (e.g. physiotherapy) when appropriate, in planning a programme for my child and incorporate specialist input into daily home/school activities		
Staff have opportunities to further their education through in-service, workshops or other educational avenues.		
Staff recognize the importance of providing a range of options for parent involvement in the preschool programme and structure services to facilitate this		
Staff are able to establish and maintain good working relationships with parents		
PROGRAMME COMPONENTS		
My child's needs are continually evaluated		
Functional assessments are used in such a way that they accurately reflect my child's abilities		
The programme emphasizes the development of social, communicative, and cognitive skills		
The programme focuses on my child's strengths, and interests and activities are planned which build on these		

Annotated Bibliography

The following lists of resources may provide you with direction for further development in pursuing a partnership relationship. We have selected books and articles which we highly recommend. These lists are arbitrarily divided, overlapping and by no means exhaustive. We apologize for any glaring omissions.

The field is currently being flooded with excellent materials relating to parent-professional partnerships. We ask for your help in updating these lists by filling in and mailing the enclosed form. The form is located at the back of this book.

PART III: RESOURCES

An Historical Perspective

Heifetz, L.J. From Consumer to Middleman: Emerging roles for parents in the network of services for retarded children. R.R. Abidin (ed.) In: Parent Education & Intervention Handbook. Springfield, Illinois: Charles C. Thomas, Pub. 1980.

This article gives an insightful and indepth overview of recent changes in the role of parents and professionals in working together. Like pieces of a puzzle, Heifetz fits together trends within the field of mental retardation, showing us how far we have come, and some of what's ahead. His approach is theoretical, extremely thought provoking and perceptive.

National Institute on Mental Retardation (N.I.M.R.) Orientation Manual On Mental Retardation Pt. 1 (Revised Edition) Downsview, Ontario: Kinsmen NIMR Building, York University. 1981. $7.50.

Here is a comprehensive look at key issues influencing the development of Canadian services for the mentally retarded. This manual covers groundwork such as the history of services, the development of parent organizations and the philosophy of normalization. It is an excellent reference book for parents, professionals, and all those who wish to deepen their understanding of mental retardation services.

Sarason, S.B. & Doris, J. Educational Handicap, Public Policy and Social History: A broadened perspective on mental retardation. New York: The Free Press, 1979.

This book examines the field of mental retardation, "as a window through which to view our society". Written by two well known authorities on mental retardation, this book challenges traditional concepts relating to diagnosis and management, the role and training of professionals and institutionalization. It shows how changes within the field of mental retardation reflect changes in our larger society.

Blatt, B. Introduction: The Threatened Planet. In: Parents Speak Out! Views from the Other Side of the Two Way Mirror. Turnbull, A.R. & Turnbull, H.R. (eds), Columbus, Ohio: Bell & Howell Co., 1978.

Blatt, B. & Kaplan F. Christmas In Purgatory. Boston: Allyn & Bacon, 1966.

Hobbs, N. Issues In the Classification Of Children (2 Vols). San Francisco: Jossey-Bass, 1978.

Wolfensberger, W. Normalization. Toronto: National Institute on Mental Retardation, 1972.

General Parenting and Child Development

Braga, Laurie & Joseph. Learning And growing: A guide to child development. Englewoods Cliffs, N.J.: Prentice-Hall, Inc., 1975.

This book is a goldmine of information about young children and their development. A chapter is devoted to each of the pre-school years including:birth - 1: the beginning; 1-2: feeling their oats; 2-3: I want it my way; 3-4: the age of reason; 4-5: the calm before the storm. Additional chapters look at school, materials and resources. The authors clearly have a deep understanding of child development and what parents can do to help their children.

Leach, P. Your Baby and Child From Birth to Age Five. New York: Alfred A. Knopf, 1981. 512 pages.

This is an encyclopedia of practical information about the development of young children written for parents. In a simple yet thorough fashion Leach covers a wealth of topics, from care of the newborn to coping with sibling rivalry. This book is beautifully illustrated with photographs. It is rapidly replacing Dr. Spock on many parents bedside tables.

Stern, D. The First Relationship: Infant and Mother. Cambridge, Massachusetts: Harvard University Press, 1977.

Some of the details of how mother and young infant commonly behave together are described in this book. Stern's knowledge comes from his work as a researcher in carefully analizing high speed motion pictures of babies and mothers interacting. Somehow he is able to translate his highly technical scientific findings into a sensitive and very readable book. He shows how spontaneous play between mother and infant are in fact like a dance, exquisitely choreographed by nature to teach the infant in 'the ways of things human'.

Boston Womens Health Book Collective. Ourselves & Our Children. New York: Random House, 1978.

Birch, H. and Chess, J. Your Child Is A Person. New York: Viking Press, 1965.

Braga, Joseph and Braga, Laurie. Growing With Children. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1974.

Brazelton, T.B. Toddlers And Parents: A declaration of independence. New York: Delacorte, 1974.

Brazelton, T.B. Infants & Mothers: Differences in development. New York: Dell Publishing Co., 1969.

Brazelton, T.B. On Becoming A Family.

Dreikurs, R. Children The Challenge. Illinois.

Elkind, David. The Hurried Child: Growing up too fast too soon. Reading, Massachusetts: Addison-Wesley Pub. Co., 1981.

McDiarmid, N.J.; Peterson, M.A. and Sutherland, J.R. Loving And Learning: Interacting with your child from birth to three. New York: Harcourt Brace Jovanovich, 1975.

Pogrebin, L.C. Growing Up Free: Raising your child in the 80's. New York: McGraw-Hill Book Co., 1980.

Parent Development:

Specific to Special Developmental Needs

Featherstone, H. A Difference In The Family: Life with a disabled child. New York: Basic Books, 1980.

This is an exceptionally sensitive and genuinely helpful book about the impact of a child who is different on the family. Written by a professional educator who is also the mother of a severely disabled child, this book combines insights from both the parent and the professional perspective. This is a rare book that touches everybody, whether parent, professional, relative, friend or neighbor.

Mitchell, David. Your Child Is Different: A handbook for parents of young children with special needs. Sydney and London: George Allen and Unwin, 1982. Aust. $4.95.

This handbook gives practical suggestions for ways in which parents can help their young children with special needs. In a style which is consistently straight forward, informative and understanding, this booklet provides many helpful hints. It is written by people in the fields of psychology, teaching and speech therapy.

Perske, R. New Directions For Parents Of Persons Who Are Retarded. Nashville: Abingdon Press, 1973.

This book has rapidly become a classic in helping parents to adjust to having a handicapped child. Perske has a special ability to cut through to the core of common concerns and fears in a way that builds upon ones understanding and personal strength. His deep respect for individuals with special needs and their parents is clearly the guiding light of his work. This book's loving illustrations are done by Perske's wife Martha.

Biklen, D. Let Our Children Go: An organizing manual for advocates and parents. Syracuse, New York: Human Policy Press, 1974.

Coordinating Council for Handicapped Children. How To Get Services By Being Assertive. Chicago, Illinois: 1980.

Coordinating Council for Handicapped Children. How to Organize an Effective Parent/Advocary Group and Move Bureaucracies. Chicago, Illinois: 1980.

Cunningham, C.C. and Sloper, P. Helping Your Exceptional Baby. New York: Pantheon Books, 1978.

The Exceptional Parent. P.O. Box 4944, Manchester, New Hampshire, U.S.A. 03108.

Tatelbaum, J. The Courage To Grieve. New York: Lippincott & Crowell, 1980.

Parents' Stories

Dougan, Terrell; Isbell, Lyn; Vyas, Patricia (eds). We Have Been There: A Guidebook for Parents of people with mental retardation. Salt Lake City, Utah: Dougan, Isbell & Vyas Associates, 1979. Dougan, Isbell & Vyas Associates, 1346 Roxbury Road, Salt Lake City, Utah, 84108.

This is a collection of 'opinions and notes from the heart' written by forty-two members of the Utah Association for Retarded Citizens. The articles are arranged into sections: How to survive what the doctor just told you, What to do with a pre-schooler, Your child, School, The law and how to stand up to it all; Looking back; Growing; Changing, Moving out; What of the brothers and sisters; What's an A.R.C.?; Services, how to get them, how to improve them; Anger; and Who are they. Many of the articles are written with humour, while others have a more serious tone. All contributions are intensely personal and could only have come from persons who have themselves, "been there".

Schaffer, Nicola. Does She Know She's There. Don Mills, Ontario: Fitzhenny & Whiteside Ltd., 1978.

This is a delightful Canadian account of a mother's experiences with her multiply handicapped daughter. Rarely could one imagine a book about such a vulnerable experience written with such humour. Somehow Schaffer manages to get across the essence of her life with her daughter: the day-to-day realities, the frustrations and the intimate joys.

Turnbull, A.P. and Turnbull, H.R. Parents Speak Out: Views from the other side of the two-way mirror. Columbus, Ohio: Charles E. Merrill Pub. Co., (Bell & Howell Co.), 1978.

This book is written by parents who are also professionals. Whether professor, pediatrician or lawyer, the authors candidly present intimate descriptions of their experiences as parents of handicapped children. "The people whose words you read here have survived in spite of professionals, not because of them. There are many lessons for would be helpers to learn from these stories: respect for parental competance, humility in the face of one's own ignorance, acceptance of the contributions of other professional disciplines; but they all stem from the eloquently simple tenet of the physicians code: DO NO HARM".

Bennett, J. Company, Halt! In: A.P. Turnbull and H.R. Turnbull III, Parents Speak Out: Views from the other side of the two-way mirror. Columbus, Ohio: Charles E. Merrill Pub. Co., 1978.

Buck, Pearl. The Child Who Never Grew. New York: John Day, 1930.

Featherstone, H. A Difference In The Family: Life with a disabled child. New York: Basic Books, 1980.

Greenfield, J. A Child Called Noah. New York: Holt, Rinehart & Winston, 1972.

Greenfield, R. & Massie, S. A Place For Noah. New York: Holt, Rinehart & Winston, 1978.

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Roos, R. Parents Of Mentally Retarded Persons. Int. Journal of Mental Health, 1977. 6(1), pages 96 - 119.

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Teelucksingh, B. Talking To Melainie: A mother's experience with language development. The Exceptional Parent, June 1980, pages 8 - 12.

Turnbull, A.P. Growing With A Handicapped Child In The Family And Community: A parent's perspective. In: J.L. Paul (ed), Handicapped Children & Their Families in Church and Community. Syracuse, New York: Syracuse University Press.

Vyas, Pat. Getting On With It. In: We Have Been There: A guidebook for parents of people with mental retardation. Salt Lake City, Utah: Dougan, T., Isbell, L. & Vyas, P. (eds), Dougan, Isbell & Vyas Associates, 1979.

First Person Accounts

Bogdan, R. and Taylor, S. Inside Out: The social meaning of mental retardation. Toronto: University of Toronto Press, 1982.

Two autobiographical accounts of what it means to be labled mentally retarded, told by 'Ed Murphy and Pattie Burt' who grew up in institutions for the retarded. The interviewers argue that Ed and Patti turn your preconceptions about mental retardation 'inside out'. Read it - your perceptions will change.

Deloach, C. and Greer, B.G. Adjustment To Severe Physical Disability: A metamorphosis. New York: McGraw-Hill Book Co., 1982.

Putman, Marie. Mentally Handicapped Love. Madiera Park, B.C.: Harbour Publishing, 1981.

Meyers, R. Like Normal People. New York: McGraw-Hill, 1978.

A Family Perspective

DuBose, R.F. (Issue Editor). Families of Young Handicapped Children. Topics in Early Childhood Special Education, 1(3), 1981.

This special journal issue focuses on helping professionals improve their work with children by developing a family perspective. A child is a member of a family with its own priorities, needs and lifestyle. The need for professionals to understand and respect these individual family differences is emphasized. Guidelines are given for how professionals can develop effective programmes for parents of young children with handicaps.

Beail, N. and McGuire, J. (eds). Fathers of Mentally Handicapped Children. Psychological Aspects of Fatherhood. London: Junction Press, 1982.

Beckman-Bell, P. Child-Related Stress In Families Of Handicapped Children. Topics in early childhood special education, Vol. No. 3, 1981, page 45 - 54.

Bristol, M.M. and Gallagher, J.J. A family focus for intervention. In: Ramey, C. and Trohanis, P. (eds), Finding and Educating the High Risk and Handicapped Infant. Baltimore: University Park Press, 1982.

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This is a greatly needed book which describes in detail and with clarity how professionals can help parents and infants interact with each other. Bromwich presents an approach to early intervention which puts into practice the theory of parent-professional partnership. Her approach is based on the belief that there is no 'best' way for professionals to help parents. Instead, Bromwich emphasizes the need for professionals to learn skills in supporting, informing and encouraging parents to help them solve their own problems. This book is a must for all professionals working in the field of early intervention.

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This textbook gives information and suggestions to help teachers and parents develop cooperative educational planning and programming for handicapped children. Articles are written from a variety of perspectives: the parents, the handicapped individual, the educator, public social policy and the law. This is a comprehensive book written by people who have clearly given a great deal of thought to issues raised by the increasing involvement of parents in educational decisions that effect their children. Although the discussion is based on the American experience with Public Law, 94-142, it certainly has important implications for Canadians as well.

Sax, P. Counselling Parents.

This paper traces the evolution of parent/professional relationships in North America and attributes major changes in services and professional practices to the parent movement. Research findings presented advise greater professional awareness of, and respect for, the individuality and complicity of the parent role. This paper is available in limited quantities from the Office of the Provincial Advisor, IDP - 2979 W. 41st Ave. Vancouver, B.C., V6N 3C8, at $5.00 a copy.

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This article traces changes in the objectives of the field of early intervention. Whereas the emphasis in the past was on stimulating the young infant as much as possible, the current trend involves helping the parents become better attuned to their infant. Bromwich argues concisely and convincingly as to why this change is critical for professionals to really make a difference in their work.

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(3) medical treatment
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Resource Recommendation

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Footnotes

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